Information for patients and families

Read this information to learn:

• how donating your brain helps
• how it can be arranged
• how to donate to the program
• who to talk to if you have any questions

The Morton & Gloria Shulman Movement Disorders Centre and The Edmond J Safra Program in Parkinson’s Disease
Brain Donation & Autopsy Program
How does donating my brain help?

Donating your brain can help researchers find out more about the causes of movement disorders. This helps them come closer to finding a cure for disorders like:

- Parkinson’s disease
- Progressive Supranuclear Palsy
- Multiple System Atrophy
- Dystonia

Donating your brain also:

- helps your family understand your diagnosis. This may help future family members
- helps researchers learn important information. This helps them know more about Parkinson’s disease and other movement disorders.
- gives you a chance to help improve future care and treatments for patients with movement disorders

Who can donate?

Every Movement Disorder Centre (MDS) patient can donate.

Will donating affect my funeral arrangements?

Donating your brain will not affect your funeral arrangements. A specially trained neuropathologist does the procedure very carefully as soon as possible after you die. Your family will not have to wait to make funeral arrangements. Because it is done so carefully, your family could still arrange for an open casket.

Please let the MDS staff know about any funeral arrangements ahead of time. Talk with our staff if you are worried about timing.
Will donating my brain cost anything?

No. MDS will pay for all of the costs of the donation. Your family would still be responsible for the costs of the funeral and burial.

Financial donations are very important to our program. We greatly appreciate any money you or your family could donate for transportation and other costs.

How can I give to the program?

Gifts to the Brain Donation program are an important source of funding. We appreciate donations of any amount. If you wish to make a tax deductible donation, please make cheques payable to:

Brain Donation Program
Movement Disorders Centre Research Fund
399 Bathurst St., 7 McLaughlin Pavilion, Room 402
Toronto, ON M5T 2S8
How can I arrange brain donation?

MDS staff can talk to you and your family about brain donation.

All we need to go ahead with the donation is a signed consent. This is a letter that explains what will happen. You sign it to say that you agree to the procedure.

Please ask your doctor or nurse for more information and how to get the forms you need. Staff at MDS will help you through the process.

Can my family learn the results of the study?

Yes. Let MDS staff know that your family will want to know the results of the study. It can take many months for these reports to be ready. When they are ready, the movement disorders neurologist will talk to your family about the results.

Will my religion support brain donation?

Most major religions support brain donation. This is because it helps researchers, future patients and families.

Speak with your spiritual leader if you want to know whether your religion supports removing a body part (organ) after death.

For more information about religious and cultural beliefs about donating organs, please visit the Trillium Gift of Life’s website at [www.giftoflife.on.ca](http://www.giftoflife.on.ca)
Click Donor Family Support and then click Additional Information. Here you can read about cultural and religious ideas and opinions about donation.

What if I change my mind about donation and research?

You can change your mind about donating your brain at any time. Call the MDS brain donation coordinator or your doctor to let them know as soon as possible.
Who can I talk to if I have any questions?

For more information about brain donation, speak to your movement disorders neurologist.

You can also contact:

**Yu-Yan Poon, BScN, RN - Brain Donation and Clinical Research Coordinator**
Movement Disorder Centre
McLaughlin Pavilion - 7th Floor (Room 407)
Toronto Western Hospital
399 Bathurst Street, Toronto ON M5T 2S8

**Phone:** 416 603 5875 extension 2  
**Fax:** 416 603 5004